

# UNINSURED CHILDREN IN RHODE ISLAND : RESULTS OF FOCUS GROUPS



Submitted to:  
Center for Child and Family Health  
Division of Health Care Quality, Financing & Purchasing  
Rhode Island Department of Human Services

Prepared by:  
Jane Griffin, MPH  
MCH Evaluation, Inc.  
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For more information or additional copies contact:

Jane Griffin, MPH, Project Director, Research and Evaluation  
Division of Health Care Quality, Financing and Purchasing  
Rhode Island Department of Human Services  
600 New London Avenue, Cranston, RI 02920  
1-401-462-6367

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The most important contribution to this report came from the families who participated in the focus groups. Their stories of the difficulties they faced trying to get health insurance and the negative consequences on their childrens' lives is testimony to the importance of trying to find ways to reach these families. One mother, of four who participated in the focus group and whose husband had recently been laid off and lost his health benefits, summarized the problem,

*If a child doesn't have health insurance they are still a child. When I had health insurance, if anything happened we could just take care of it. But how sad it is when you don't have it. Your first reaction when you call for care is what is this person going to say to me. First thing they ask is, "what do you have for insurance?" and when I say I don't are you going to treat me differently. I have a child as wonderful as your child, but because you have medical and I don't it puts me in a whole different category.*

Jane Griffin, MPH  
MCH Evaluation, Inc  
December 9, 1999

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## I. EXECUTIVE SUMMARY

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MCH Evaluation, Inc. conducted four focus groups with 28 parents whose children and teenagers did not have health insurance. The purpose of these focus groups was:

- To determine the reasons children and teenagers in Rhode Island did not have health insurance
- To find out the consequences on these children and parents of having no health insurance
- To design outreach strategies to help children get health insurance

### **Reasons Children are Uninsured:**

#### Health insurance offered through parent's employer was too expensive -

Many families were unable to afford the family health insurance offered by their employers. Parents worked in factories, motels, restaurants, nursing homes and social service agencies. Health insurance premiums would cost them from \$65-\$102 a week and many of them had no money left to purchase this coverage after paying rent, utilities and food.

Children's citizenship status made them ineligible for RIte Care - There were several immigrant children and teenagers with chronic medical conditions who had never had health insurance. Many had applied for RIte Care and were denied because they were not citizens. Immigrants were from South America, the Caribbean, and Africa.

Families who are denied RIte Care many times do not reapply - Several families shared stories of how their children were denied RIte Care and it was not worth the hassle of reapplying because the application process was so demeaning. Most of these families were currently eligible.

## **Consequences of Having no Insurance**

### Children and teenagers go without treatment for serious medical

conditions - Uninsured children not only go without preventive care they also do not fill prescriptions for chronic diseases and forego emergency department treatments and needed hospitalizations due to lack of insurance. Sixteen of the uninsured children had serious chronic medical conditions and were not being followed by a medical provider. Three of the mothers whose children had attention deficit disorder were unable to fill the ritalin prescriptions for their children. One mother whose child had asthma could not afford the inhaler and so went without the medication. Two children needed surgery - one will lose her voice the other will lose her vision without the surgery.

Parents pay high out-of-pocket expenses for their children ' s care - All of the families who participated were struggling with paying rent and buying food and were not able to pay unexpected health costs. Parents had unpaid medical bills ranging from \$80 - \$2,000.

Parents cannot afford medical care and drugs for their children so they resort to using home remedies, sharing prescriptions and searching for free care - Many parents try unproven therapies and use medication that is prescribed to someone else to treat there children ' s chronic medical conditions.

## **Outreach Strategies:**

Outreach brochure - The focus groups agreed that a printed brochure or flyer that could be posted, distributed to agencies or sent directly to all parents with children would be helpful. A simple message needs to be on the front that says, "Do you need health insurance for your family?" Workplace settings were the highest priority for outreach.

Different outreach strategies are needed to address the unique needs of the three major types of uninsured families -

- Working Families
- Immigrant Families
- Families who are Denied or Discontinued from RIte Care

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## **II. BACKGROUND**

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The Center for Child and Family Health (CCFH) Department of Human Services implemented the Children's Health Insurance Program (CHIP) on May 13, 1998. The purpose of this program is to expand health coverage to uninsured children up to age 18. CCFH currently administers the Medicaid Program for all children up to age 21. CCFH was interested in conducting focus groups with parents of uninsured children to help:

- Design outreach strategies to reach uninsured families
- Determine barriers to obtaining health insurance for RI families



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### **III. METHODS**

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MCH Evaluation, Inc., a Center for Child and Family Health (CCFH) research contractor, conducted the focus groups. MCH Evaluation convened a planning group to determine areas of discussion for the focus groups and to design questions to address these areas. The planning group wanted to address the following issues:

- Reason child has no coverage
- Unmet health care needs of child
- Special needs of Hispanic families
- Outreach Strategies - promote preventive care or health insurance?
- Other family problems that interfere with getting health care

A draft set of questions were developed to address these issues and were then submitted to the CCFH staff for review and comment . Revisions were made and a final set of questions was designed (Appendix 1).

MCH Evaluation, Inc. designed a recruitment flyer in both English and Spanish and posted it in over 75 agencies in the cities of Providence, Pawtucket and Central Falls (Appendix 2). Table 1 shows the types of agencies where the flyer was posted.

<b>Table 1</b> <b>Agencies where Recruitment Flyers were Posted</b>
Health Centers Community Centers YWCA 's & YMCA 's Boys & Girls Clubs Department of Labor & Training - Unemployment Office Head Start Programs Day Care Centers Emergency Shelters Hospital Emergency Rooms Housing Authorities Libraries Community Action Programs Child Advocacy Agencies Churches Laundromats Supermarkets

Fifty phone calls were received in response to the recruitment flyers. Each person who called was asked twelve questions to screen and assign them into the appropriate focus group (Appendix 3).

Parents were sent a reminder flyer a few days before the focus groups (Appendix 4). Four focus groups were held from April 1999 - June 1999 in a hotel meeting room. Two were conducted in the morning and two in the evening. A meal was served at each focus group. Three were conducted in English and one in Spanish. An introductory statement was read (Appendix 5) and a facilitator asked the open-ended questions. The focus groups were taped and a recorder took notes (Appendix 6). Parents were paid \$50 to participate and were reimbursed for babysitting and transportation.

At the end of each focus group a CCFH representative explained the RIté Care program and the new mail-in application. The mail-in application was distributed to all participants. The tape recording of each meeting was transcribed, the transcriptions were reviewed, major issues were outlined and quotations were selected to illustrate the parents' opinions.

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#### IV. RESULTS

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Thirty seven parents called in response to seeing a recruitment flyer. Thirty-two were assigned to groups and 28 participated in the focus groups (87.5 %). Table 2 shows the characteristics of the focus groups participants.

<b>Table 2</b> <b>Characteristics of Focus group Participants</b> <b>(n = 28 )</b>	
Total number of uninsured children	39
Age range of uninsured children	6 mos - 18 years
% Minority	79%
% Hispanic	61%
% Living in Providence	33%

## **A. Reasons Children are Uninsured**

There were three major reasons children and teenagers in these families were uninsured.

- Health Insurance offered through parents employer was too expensive
- Children ' s citizenship status made them ineligible for Rlte Care
- Many families who are denied Rlte Care do not reapply

Following is a brief discussion of the three issues with quotations from parents to illustrate the impact of these issues.

### 1. Health Insurance offered through parents employer is too expensive

Nine of the families who participated were unable to afford the health insurance offered through their employers. The cost of family health coverage ranged from \$65 - \$102 per week. Focus group participants worked in restaurants, jewelry factories, nursing homes, hotels and social service agencies.

Two single mothers shared their frustration of trying to pay for health insurance out of their paycheck. One mother of three school-aged children who works as a restaurant chef said,

*I' m struggling right now. I' m not asking for cash benefits. I' m not asking for food. All I want is medical. In my job, a single plan is \$52 every two weeks but for a family plan it' s \$73 every week which is \$156 every two weeks. I cannot afford \$156 every two weeks. I don' t make that much money. It' s stupid, you know. Plus, I have to pay for parking and all that stuff and I only work 37 hours a week. My rent is \$450. I pay \$100 a month for oil, never mind the electricity. I need a phone and never mind about toilet paper. Now I need to buy my own food. I tried to get food stamps before but they gave me a run around about that too, so I' m not even bothering. Why do I have to struggle?*

Another mother with a college degree in social services who works at a community center said,

*For me to have my daughter on health benefits it' s \$400 a month through my job. I' ve taken a pay cut before so that she can have health insurance. I' m not doing it again. I' m going to fight this all the way if my daughter doesn' t qualify for insurance because I can' t afford it. You have to be able to make it in the world. One day I would like to buy my house. I would like to finish painting my house, but health insurance is just ridiculous. You know she' s a healthy child, but you never know.*

Two participants who had recently been laid off could not pay the COBRA fee of \$450 a month to continue their family health coverage. One single mother said,

*I' m paying \$111 co-pay a month for Health Mate and Dental. When I get asked to leave, I' ll be paying \$458 for Cobra. Without any other income except my own, there' s no way that I' ll be able to afford that kind of money.*

## 2. Children's citizenship status makes them ineligible for RIte Care

There were twelve children who were uninsured because they were not United States citizens. Most were immigrants from South America, the Caribbean and Africa. Children had been uninsured up to 15 years and many had chronic health conditions that went untreated.

One Hispanic mother whose daughter needed surgery on her tonsils, so she would not lose her voice, expressed her frustration,

*I have an 11 year old daughter and I have been trying everything to have, you know, health insurance because she doesn't have a social security number and I am trying every way for her to have one, you know. She really needs to have an operation and she can't because everywhere I go they tell me you don't have a social security number so you are not able to qualify. I tried going to many places asking for help because I paid whatever I had, sometimes \$100 for 24 months. My daughter, she's trying to talk with her voice but her tonsils, you know, need to be taken out and she has been like this for three years and its getting worse.*

Another Hispanic mother who was extremely distraught about her 15 year old son, who had severe behavioral problems, shared her situation,

*I have a 15 year old son who doesn't have medical insurance. He came to this country when he was three years old. He has ADD and I try hard to look after him, but they told me because he is not a citizen he does not qualify for RIte Care. I know he needs all kinds of medication, you know, all kinds of treatment. He was in treatment with a pediatrician, but he no longer gets the treatment he's supposed to get. The situation has gotten much worse. I have to keep him in the house all of the time. The school told me if I didn't get medication for him he's out of school.*

### 3. Many Families who are denied RIte Care do not reapply

Several families shared stories of how their children were denied or discontinued from RIte Care and it was not worth the hassle of reapplying. They felt the application process was humiliating. One homeless mother, whose daughter had high lead levels, decided it wasn't worth the effort to put up with all the obstacles to apply for benefits. She said,

*We moved to RI in August and I applied for benefits and they canceled it because I didn't have the birth certificate, but I didn't have the money to get a copy of the birth certificate so I requested that they send for it. When I went through the second interview where they actually go through your documentation, I just felt like I was doing something wrong. I feel like health care should be for everybody. When I called her back about the birth certificate, she was really nasty and told me that it was my fault I didn't get the birth certificate. I said well I filled out the form and you said you would send it in to the registry down here and I thought they'd just send it over in a two week time period like you said it would be. She said, "well you know I have 300 people to look after and I don't have time for you". I said all right, see you. That's fine. I guess I got really fed up, you know, it's just too much paperwork and too much aggravation and the people who work down there are really nasty. I felt like instead of helping you in a time of despair, they don't. They make you feel like you're worthless. So I didn't want to become part of that.*

Many mothers felt they were treated unfairly when they applied for benefits because English was not their primary language. One mother said,

*The DHS workers treated me very rude. When you want to apply for something once you have an accent that's a problem. They think they are the ones giving you the money. Like they don't want to give it to you. You're not giving it to me, I just want to apply. If I qualify fine. They give you a hard time because of the language or because they see you're from another country.*



Reasons for denial or discontinuation of RItE Care by these focus group participant included:

- Child turned 18, but still in school
- Income too high
- Cash assistance ended, so mother assumed that included RItE Care benefits
- Moved and did not receive denial letter til after 10 day appeal period
- Unable to afford copy of child ' s birth certificate
- Not a United States citizen

Many of these children would be eligible for RItE Care under new eligibility guidelines, but parents were unaware of the new changes and assumed their children were ineligible.

## **B. Consequences of Having no Health Insurance**

Children without health insurance and their parents suffer many negative consequences. The major consequences experienced by these focus group participants included:

- Children and teenagers go without treatment for serious medical conditions
- Parents pay high out-of-pocket expenses to get health care for their uninsured children
- Parents cannot afford medical care for their children so they resort to using home remedies, sharing prescriptions and searching for free medical care

1. Children and Teenagers go without treatment for serious medical conditions

Sixteen of the uninsured children who had serious chronic medical conditions or disabilities, were not being followed by a medical provider. Table 3 shows the 16 chronic conditions represented in the focus groups. These children lacked continuity of care and in many cases were not receiving treatment or medication for their condition.

<b>Table 3 Children 's Chronic Conditions Represented in Focus Groups</b>	
4	Asthma
4	Attention Deficit Disorder
3	Allergies/Eczema
1	Larynx problems, needed surgery (no voice)
1	Back injury
1	Lead Poisoning
1	Heart defect
1	Vision problem requiring surgery

Many children had become more disabled over the years due to lack of care and medication. One mother whose daughter needed ritalin for severe attention deficit hypertension disorder said,

My eight year old daughter has ADHD. She needs ritalin every day for school. She needs the medication. What am I going to do? I work and I've got like 30 cents left out of my check after I pay for food, rent, and oil. It's really difficult, it is really, really tough.

Three of the mothers whose children had attention deficit disorder were unable to fill the ritalin prescriptions for their children.

Two of the children needed surgery - one on her larynx so she wouldn't lose her voice and one on her eyes so she wouldn't lose her vision. One mother who couldn't afford preventive care for her 2 ½ year old daughter with an elevated lead level, shared her frustration with trying to get care,

*I took a part-time job but they won't hire me full-time with benefits because it was not in the budget so I'm part-time and I just don't make enough money for health insurance right now. She's been really healthy so far. She did have a problem with lead when she was a baby so I had her blood tested but I haven't recently because it costs money to have it done and I owe a few places for a few blood tests already so you kind of run out of places that you can go.*

One mother could not afford the inhaler medication for her daughter's asthma and against her pharmacist's advice did not fill the prescription,

*For my daughter, there is a lot of times I can't get medication. I explained to the doctor that I didn't have insurance because sometimes they give free medication. He gave me a prescription and told me to go to a CVS or Brooks and ask to get it for \$10 or \$20. That's all I can do. I went and it was \$70 and I said you can keep it because I don't have the money. The pharmacist was like she really needs it and I said well she needs it, but I cannot pay for it. Where am I going to get that money, where?*

Some parents even withhold emergency treatment for their children because they cannot afford the treatment. One mother who always had health insurance until her husband was recently laid off shared,

*My son had a baseball injury last week and he pulled a muscle or something and had pain all night traveling down his back. How sad that I held off and didn't take him to the ER. How sad that when your son is in pain you can't help. I felt I couldn't take him without insurance. It would have been \$85 just for the visit, that's just the visit, if he needed anything else forget it.*

## 2. Parents pay high out-of-pocket expenses for their children's care

The majority of parents participating in these focus groups were struggling to pay rent and buy food with their existing paycheck. There was limited money to pay for unexpected and ongoing health care expenses. Parents were paying the following out-of-pocket medical expenses for their uninsured children:

- Physical exams
- Prescription drugs
- Over-the-counter drugs
- Laboratory tests
- Dental care
- Emergency Department treatments
- Hospitalizations

One father of four who recently lost his job and health insurance had almost \$300 in health and dental expenses from the previous week. He shared with the group,

*My son had a check-up that was \$85. Then his eczema medication cost \$14 and his asthma medication cost \$75. That's a lot of money. My daughter had two fillings and it cost me \$118 and a teeth cleaning which was \$75. It's incredible and they want the money right up front.*

Parents had unpaid medical bills ranging from \$80 - \$2,000.

3. Parents cannot afford medical care and drugs for their children so they resort to using home remedies, sharing prescriptions and searching for free care

Many of the parents with the focus groups were unable to afford medical care for their children so they resorted to the following strategies to get the care and treatment their children needed:

- Home remedies
- Prescription sharing
- Free medical care clinics

Some of the home remedies parents tried on their children were ginger and menthol for sinusitis and herbs and spices mixed with oil for asthma. Most parents said the home remedies did help, but would prefer getting a prescription from a physician.

Several mothers had shared prescription drugs left over from other children. For example, one mother used antibiotics her son was on for a sinus problem to treat her uninsured daughter who had an earache,

*If you have a kid that doesn't have medical coverage you do what you can. One time she was complaining of an earache and I had antibiotics for my son because he gets sinus infections, so I had no choice, I had to give her that because I couldn't take her to the doctor because I couldn't afford it. Thank God it worked.*

Parents had also found several sites that provided free preventive care. These free sites that parents had used included:

- Travelers Aid - checkups and eyeglasses
- Bristol Community College - dental care
- St. Joseph - free immunization and lead screening
- Notre Dame Hospital - mammogram



### **C. Outreach Strategies**

All the focus group participants were asked how the RItE Care could reach families who did not have health insurance. They agreed that a printed brochure or flyer that could be posted, distributed to agencies or sent directly to all parents with children (i.e., mailed or sent home from school) would be the best way to reach all families. The groups designed the contents of a brochure and suggested where it should be distributed.

#### 1. Contents of the Outreach Brochure

The focus group participants agreed that the front cover of the brochure should be simple and easy to understand with this question

**“Do you need health insurance for your family?”** in big, bold letters. The group recommended that there should be a picture with a child and a doctor in a medical setting also on the front cover. Parents agreed that inside the brochure should include:

- Listing of the benefits (e.g. doctor visits, dental, specialty care, prescription medicine, lab work)
- Phone number to call about how to apply

Parents thought inside the brochure should also include some messages such as

“RItE Care is for Working Parents and their Families” or

“Free Medical Care for your Family.”

## 2. Distribution of Outreach Brochure

Focus group participants suggested several methods and places to distribute the outreach brochure.

Suggested methods for distribution:

- Post brochure in community agencies and settings
- Direct mail brochure to all parents in the state
- Send brochure home with all school children

Table 4 shows the places to distribute the brochure suggested by the parents.

<b>Table 4</b> <b>Places to Distribute Outreach Brochure to Reach Uninsured</b>
Workplace (Priority site - mentioned in all groups)
Department of Labor & Training - Unemployment Sites
Temporary Employment Agencies
Schools & Colleges
YMCA or YWCA
Boys & Girls Clubs
Supermarkets
Fast Food Places
Laundromats
Libraries
Hair Salons

The workplace setting was the top priority site for distribution. Parents suggested employee bulletin boards in factories, restaurants, nursing homes and other small businesses.

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## **V. RECOMMENDATIONS**

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The major findings from these four focus groups are that families in Rhode Island are uninsured because:

- Health insurance offered through employer is too expensive
- Citizenship status makes children ineligible for RItE Care
- Families who are denied RItE Care may never reapply

Different outreach strategies that address the unique needs of these three types of families - working families, immigrant families, and families who are denied or discontinued from RItE Care - need to be developed.

Following are some strategies for reaching these different families:

### 1. Reaching Working Parents

There are many working parents in Rhode Island who cannot afford the family health insurance offered through their employer. In addition there are many employees who are laid off and cannot afford the COBRA insurance benefit that allows unemployed workers to continue with their health benefits for 18 months. Some recommendations to reach working families include:

- Provide RItE Care outreach materials to all employers in RI, including mail-in applications
- Distribute information to employee benefits counselors, Chamber of Commerce mailing lists

### 2. Reaching Immigrant Families

RItE Care eligibility for immigrant children has recently expanded. Many immigrant families and the agencies that provide services to these families are unaware of the new eligibility expansions. Some recommendations to reach immigrant families:

- Provide RItE Care outreach material to Immigration Naturalization Service
- Develop easy one page reference sheet to explain new eligibility requirements for immigrant children
- Meet with and distribute RItE Care outreach materials and mail-in applications to agencies and sites that serve immigrants (e.g., advocacy groups, ethnic markets, ethnic newspapers, places of worship)

### 3. Reaching Families who are Denied or Discontinued from RItE Care

Many of the parents who apply for RItE Care health benefits and are denied never reapply, even though they may be eligible. In addition, many families who are discontinued from cash benefits, do not reapply for RItE Care. Some strategies to help these families include:

- Follow-up on RItE Care incomplete applications and denials that now qualify under new eligibility requirements (e.g., income, immigrant, 18 year olds) to re-determine eligibility
- Send mail-in application to all FIP (Family Independence Program) clients who are being discontinued for cash benefits
- Conduct focus groups with DHS eligibility technicians to find the best way to provide them with new RItE Care eligibility requirements (e.g., in-service, easy reference guide, videos etc)

## **Appendix 1: Focus Group Questions**

**Reason no coverage**

3. If your child has had health insurance, please describe the different kinds he/she has had? What was the reason coverage stopped? How long has your child been without health insurance in the past year? What has it been like trying to get health insurance for your child? If working, does your employer offer health insurance? Is it affordable?

**Consequences of no coverage**

4. If you ever had gaps in coverage, what happened when your child was sick ? Did you ever delay getting care or have a doctor refuse to see you because you didn't have insurance? Did you ever use the ER because no doctor would see your child?

**Health care needs of child**

5. Does your child, without insurance, have a regular doctor? Where do you usually take him/her for care? Does he/she have any special health care needs? Did you ever use the ER? What happened?

**Outreach strategies**

6. What are some ways we can reach families, like yours, who may not have enough health insurance? (Make a list of strategies and prioritize **\*\*note:** market health benefits or insurance as prevention))

**Other family priorities**

7. Do you feel that there are other reasons, besides not having health insurance, that may prevent parents from getting health care for their children? Are there other issues that your family is dealing with that are more pressing or urgent than being without health insurance? Tell me about some of these. (Then prioritize these issues with group)

**Rlte Care Recognition**

8. Have you ever heard of Rlte Care or Medicaid? What have you heard about it? Have you ever heard of or seen their mail-in application? Has anyone here ever applied? What happened when you applied? What were some reasons that stopped you from applying?



## **Appendix 2: Recruitment Flyer**

# *Do Your Children or Teenagers Need Health Insurance?*



We need your help!  
Please join us in a focus group where  
we will talk about what it is like to  
try and get health insurance for your  
children.

*Parents will be paid for their  
participation  
&  
Transportation and child care will be  
reimbursed*

Please call Holly at 462-6367 for details

Refreshments will be served

*Sponsored by the Center for Child & Family Health  
Department of Human Services*

# *Necesitan Seguro de Salud sus Ninos o Adolescentes?*



*Necesitamos su colaboracion!*

*Por favor, unase a nuestro grupo de  
enfoco, para que conversemos acerca de lo  
que significa tratar de conseguir seguro  
medico para sus ninos.*

*Los padres seran remunerados por su  
participacion  
y ademas  
se les reembolsaran los gastos de  
transporte y cuidado  
de los ninos*

*Para mas informacion, por favor llame al 1-800-  
299-8444*

*Se serviran bebidas y refrescos*

*Auspiciados por el Centro para la Salud del Nino y  
de la Familia  
Departamento de Servicios Humanos*

## **Appendix 3: Phone Call Protocol**

Focus Group - Uninsured  
Screening & Assignment Phone Call

1. Date of Call \_\_\_\_\_

2. ID# (assign Chronologically) \_\_\_\_\_

3. Thank you for calling. The Center for Child and Family Health is conducting a series of focus groups with parents to find out what is like to try and get health insurance for children in Rhode Island. Your ideas and opinions will help us improve health insurance programs for children. Each parent will receive \$50 for their participation in this 2 hour group meeting. Are you interested?

I need to ask a few questions for group placement.

Name: \_\_\_\_\_

A) What city do you live in? \_\_\_\_\_

B) How many children under 19 do you have? \_\_\_\_\_  
(List each separately) & how long have they  
been without health insurance in the past year? \_\_\_\_\_

E) What race/ethnicity do you identify with? \_\_\_\_\_

F) What language is spoken in your home? \_\_\_\_\_

G) Is morning or evening better  
for you for a meeting? \_\_\_\_\_

H) How did you hear about the focus group?  
Where did you see the flyer? \_\_\_\_\_

4. Do you work for a health or advocacy office? \_\_\_\_\_

5. What is your address where I can send you a reminder  
flyer about the focus group? \_\_\_\_\_

6. What is your phone number? \_\_\_\_\_

7. Will you need transportation? (We pay for cab & mileage) \_\_\_\_\_

7. Will you need child care? (We pay \$5 per hour) \_\_\_\_\_

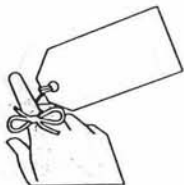
8. Do you have any questions? \_\_\_\_\_

Thank you for your information. We will call you back

9. I can assign you to a group that is meeting at the Holiday Inn  
in Providence on \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
(Wed, 4-21, 10-12 am) / (Wed, 4-28, 5-7 pm) (Wed, 6-9, 5-7 pm)

## **Appendix 4:   Reminder Flyer**

## ❧ *A Reminder About The Focus Group* ❧



We need your opinions and comments about what it is like to try and get health insurance for your children and teenagers

*When:* Wednesday, April 21, 1999

*Where:* Holiday Inn in Downtown Providence  
Hartwell Room

*Time:* 10:00 am to 12:00 noon

⌚ please come 15 minutes early, because we will start right at 10

*We will pay for transportation and childcare*

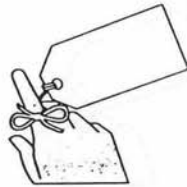
**\* A Continental Breakfast is provided \***

→ *You will be paid \$50.00 for your participation in the focus group*

Please call Holly at 462-6367 if you have any questions.

☺ Sponsored by The Center for Child & Family Health ☺  
Department of Human Services

## ☛ *A Reminder About The Focus Group* ☛



We need your opinions and comments about what it is like to try and get health insurance for your children and teenagers

*When:* Wednesday, April 28, 1999

*Where:* Holiday Inn in Downtown Providence  
Hartwell Room

*Time:* 5:00 pm to 7:00 pm

⌚ please come 15 minutes early, because we will start right at 5

*We will pay for transportation and childcare*

*\* Sandwiches and dessert will be served \**

→ *You will be paid \$50.00 for your participation in the focus group*

Please call Holly at 462-6367 if you have any questions.

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## *A Reminder About The Focus Group*

We need your opinions and comments about what it is like to try and get health insurance for your children and teenagers

*When:* Wednesday, June 9, 1999

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## **Appendix 5:    Introductory Statement**

### FOCUS GROUP- INTRODUCTORY STATEMENT

Introduce self.

Thank you for coming today. You are probably wondering what is a focus group. Focus groups are used to develop new services and products. For example, how to make cereal sell by testing different cereal packages. The Department of Human Services has done a series of focus groups to find out if consumers are satisfied with the medical care services they are receiving. Services involving prenatal care, pediatric care, dental care, mental health services and so forth...

Our focus group today is with parents who are trying to get health insurance for their children or teenagers. We need your ideas and opinions about what it is like to get health insurance and how we can reach out to other parents like yourself.

Your answers are private and will not be shared with anyone. I will tape this as we talk because I cannot remember everything that we say and do not want to miss any of your comments. We will listen to the tape and write down your opinions and ideas. We will not use your name. If you want to say something and don't want it recorded, we can turn the recorder off. You only have to answer the questions you want to and you may leave the meeting at any time. Remember, there are no right or wrong answers. It helps us the most if you just tell us what happened with you when you tried to get health insurance for your child.

My job is to make sure we get everyone's best ideas and opinion. Since we have a lot of questions to answer and only two hours, I may sometimes interrupt to move us along but I will try to bring up the other issues you raise if we have time at the end.

Break - around 6:30 for sandwiches

## **Appendix 6: Recorder's Notes/Case Studies**

## **Recorders Notes: Uninsured Children Focus Group**

### **1. Reason no coverage**

Parent and/or child not of legal status, therefore no social security number

RIte Care application denied because: (1) incomplete or missing information or (2) didn't have correct information i.e. father's info., sponsor letter etc..

Child is 18 years old

Income was too high to qualify for assistance but too low to adequately cover all living expenses i.e food, rent, utilities, day care & insurance

Parents job provided only single coverage not family, and premium was too high for parent to pick up

### **2. Consequences of no coverage**

Child needed operation and parent had to go church to church seeking money for bills, medicines

Families are not receiving regular preventive care, children are only seen when "something is really wrong"

Even the clinics are now refusing to see anyone if they do not have insurance

Parents are treating their children themselves, buying over the counter medicines and making their own medical decisions

### **3. Health care needs of child**

Children have health conditions that are going untreated, i.e. back problems, asthma, ADD

Parents are using ER's and walk-in clinics for all types of ailments and getting charged very high fees that they have to pay off a little at a time

Parents are "throwing away" prescription slips because they know that without health insurance they will be unable to afford the prescription

#### **4. Outreach strategies**

Create a new, easy to read and understand brochure in both English and Spanish

Include only the necessary information, i.e. phone number, a picture portraying that the brochure is about health/medical insurance, age of who is eligible

Put brochures at job sites, schools, community centers, laundry mats, supermarkets

Designate a community liaison for RItE Care that the community is aware of to help them fill out application and/or follow-up on it's status

#### **5. Other family priorities**

Parents want other expenses taken into consideration, i.e. rent, daycare, utilities, food etc..

All participants agreed that health insurance is the most important but they cannot afford the high premiums in addition to their other "living" not "luxury" expenses

#### **6. RItE Care recognition**

All participants were aware of RItE Care and some had children who were currently on RItE Care while others were still in early stages of applying but were still confused about guidelines and eligibility requirements

Would like to see RItE Care separate from the welfare office, one participant felt that more people would apply for RC if it wasn't "connected to welfare"

Some participants felt that some of RItE Care's application questions were too personal or unnecessary

All participants had a positive view of RItE Care and liked the fact that they could go to a private doctor at a specific health plan network

## **Case Studies**

### **Children without Health Insurance**

#### **Case Study #1**

Mother needed a physical to get into CNA program but could not get a doctor to give her one because she had no insurance. Hospital and clinic would not bill her, told her she would have to pay out of pocket and she just didn't have the money. She was told that St. Josephs had money put aside for such cases and was still refused there. She felt she was in a catch 22 situation. She wanted to get trained so that she could get a good job with health insurance for her child yet couldn't get a physical to get her into the program she needed to be in to get CNA degree.

#### **Case Study #2**

Hispanic mother who has 2 children born here who are on Rite Care but has an older child who is 14 who does not have insurance because he is not a US citizen. Older boy has severe ADD and is violent and extremely hostile & depressed. Boy needs to be treated with medication but mother cannot afford to bring him to doctor and pay for medication so she keeps him in house with her all the time except for when he is in school. She is also not a citizen but has hired several lawyers throughout the years to help her become a citizen. One lawyer told her if she married the father of her 2 small children, it would help her status. She did and was physically abused. Once she left, husband went to immigration said he didn't want to sponsor his wife anymore and now she is back where she started, less the money she paid for these lawyers who did nothing to help her. She has recently hired yet another lawyer who said he would help her with her status.

#### **Case Study #3**

Hispanic mother with an 11 yo daughter who needs to have her tonsils removed because of seriousness of condition but does not have insurance because daughter has no social security number. Mother has gone church to church looking for money to pay bills. She has thrown away or refuses prescriptions because she has no money to buy them. Her husband recently had a heart attack and was brought by ambulance to RI Hospital ER. Once they stabilized him, the first question they asked was regarding insurance, when she said that they didn't have it, they were discharged and sent home in a cab. Her husband had only his pajamas on. He has had no follow-up and no explanation. She felt "they were treated like dogs not human beings"

#### Case Study #4

Her children were in DCYF custody and has gotten runaround because DCYF has not closed her case so they can only qualify for fee-for-service not RItE Care. She said it was a hassle to go through process of adding just 1 person. Her 8 y.o. needs Ritalin and she cannot afford it. Mother is a cook at a restaurant and her paycheck does not cover her monthly expenses like - rent, utilities and food much less health insurance. She strongly feels that Medicaid and/or RItE Care should not go by gross pay when rent, utilities, food, child care, etc.. still have to come out of it, feels it is not a true reflection of how much money she has to spend on other such expenses. Insurance is not her first priority when these other expenses have to be met. She feels that working sometimes works against her because she said they when you are on welfare you can get day care and other help but because she works she does not qualify for this type of assistance.

#### Case Study #5

A middle class family who has, until recently, never been without health insurance. The father lost his job and has decided to go back to school. The parents have four children (2,9,12 & 18) and had not realized the importance of having health insurance until being without it. The mother described what it felt like when her son twisted his ankle in sports and instead of just bringing him to the emergency room to check it out, she had him wait until the next day to see if it was any better. This was because she knew they had no health insurance. She explained what a terrible feeling it is for a mother to have to see her child in pain and not be able to fix it right away because of health insurance. She felt very strongly that all children are innocent and all children should be able to go to the doctor if and when they need to.

#### Case Study #6

This homeless mother of a 2 ½ year old had been denied RItE Care because she could not afford to get a copy of her birth certificate. She relies for care on free immunization and lead screening clinics. She believes that if anything really serious comes up, her mother will help her out.



**RI Department of Human Services  
Focus Group for Uninsured Children & Teenagers**

Latino Focus Group

**held on Friday, June 25, 1999**

**at the Holiday Inn, Providence, Rhode Island**

**Notetaker and Transcriber:** *Luisa C. Murillo*

**Facilitation:** *Betty Bernal*

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## Participant Summary

**Number of Participants:** 12

### **City of Residence:**

- Providence: 5
- Pawtucket: 4
- Central Falls: 2
- Cranston: 1

### **Gender:**

- Female: 11
- Male: 1

## Latino Focus Group Report

### Reason no coverage

#### Section 1 Questions:

**If your child has had health insurance, please describe the different kinds he/she has had?**

- 7 of the 12 participants indicated that the child or children had health insurance in the past
- The types of coverage identified were: Health Mate, Medicare, Harvard Pilgrim and RItE Care
- 3 participants identified RItE Care as the type of coverage

#### **What was the reason coverage stopped?**

- 4 participants stated that DHS had cut off the coverage. The reasons given varied:
  - 2 of these 4 participants stated that a letter was never sent explaining why
  - 1 participant stated their income was determined to be too high
  - 1 participant stated that it had been due to an increase in the parent's income

**"They had taken it away because my husband had gotten an increase in his earnings," stated a participant**

- Other reasons given for why the coverage had stopped included:
  - 2 participants stated it was too expensive
  - Child was on father's coverage and coverage stopped when father was laid off
  - Self-paid health insurance became too expensive
- 2 participants stated the child was not born in the United States and had never had coverage

#### **How long has your child been without health insurance in the past year?**

- All 12 of the participants had children who were uninsured
- 7 participants stated that one or more of their uninsured children had never had health insurance
- Of these 7 participants, their immigrant children had been in the United States without health insurance since they arrived

- These 7 participants stated that their immigrant children had been here for:  
9 years, 5 years, 4 years, 2 years, 1 year
- The time lapses for the remaining 5 participants were:
  - 2 years: 1 participant
  - 1.5 years: 1 participant
  - 1 year: 2 participants
  - 3 months: 2 participants
  - 8 months: 1 participant

**What has it been like trying to get health insurance for your child?**

**"It's very difficult," stated one participant and all of the participants unanimously agreed with her.**

**If working, does your employer offer health insurance? Is it affordable?**

- 3 participants stated that their employer offered health insurance but it was too expensive
- 1 of these 3 participants cited that it would cost her \$68 per week for health insurance
- 2 participants stated that their or their spouse's employer did not offer health insurance
- 1 participant was self-employed
- 1 participant had just begun a new job and coverage did not begin for two months
- 1 participant worked part time
- 1 participant did not work but her husband did

### **Consequences of no coverage**

#### **Section 2 Questions**

**If you ever had gaps in coverage, what happened when your child was sick?**

- 2 participants stated that "thank God" the child had not been sick. 1 of these 2 participants stated that she had paid out of pocket for the child's physical exam
- 5 participants stated that they had used the hospital emergency room and all stated they still had outstanding bills
- The hospitals mentioned were: Hasbro Children's Hospital, Rhode Island Hospital and New York City Hospital
- 3 participants stated that they took their children to the community health centers
- 1 participant utilized a private physician
- 1 participant utilized Harvard Pilgrim in Providence

**A participant who had utilized the hospital emergency room stated: "The oldest fractured an arm and I had to pay a lot of money. They covered half, they helped me with half and I had to pay for the other half. A little while back I finished paying. It took me about three to four years to pay. I still have (other) bills that I am paying little by little."**



**Did you ever delay getting care or have a doctor refuse to see you because you didn't have insurance? Did you ever use the ER because no doctor would see your child?**

**Hospital emergency rooms:**

- All the participants agreed that one would not be refused care in the hospital emergency room because they have to take care of you but that you will encounter longer waiting times than someone who has insurance
- Several participants cited long waiting times in the hospital emergency room even when there were not many people in the emergency room and attributed this delay in care to not having health insurance
- One parent told her experience of visiting New York in December of 1998 and having difficulties accessing care because she was not from the state and her child was uninsured. She stated, "it was a paper mess, so many questions because I didn't live in that state. They saw her but we got there at 9 a.m. and the operation was at 8 p.m. She got to the point where she almost died... And they were waiting because I did not have health insurance...."

The participant who utilized the New York Hospital further explained, "And then once she left the hospital, she was prohibited from traveling because of her serious condition. The antibiotic cost \$25 and I did not have it. I had to go from house to house to find the money to buy the antibiotics so she wouldn't get an infection..."

Another participant who utilized the hospital emergency room stated, "They are worse, they are very cruel, they leave you in a corner and attend to those who have insurance. They treat you totally different from the ones who have insurance or those who have Medicaid."

**Delay getting care:**

- 1 participant stated, "I take them to the health center and I have a bill too. About two weeks ago my child was sick with diarrhea. I couldn't take him because I have to pay. They charge me \$20-22 for the check-up plus the medicine...And that's how he still is until now."
- 1 participant who utilized the hospital stated, "My daughter yes, I think she's missing some immunizations but I have not been able to do anything."

**Delay providing care:**

- In relation to private physicians denying care, participants stated that they indirectly would deny you care if you are uninsured because they require payment prior to the visit

One participant stated, "You have to pay. If I didn't have the \$50 they wouldn't see me."

- Another concern, expressed by a participant who utilized Harvard Pilgrim was that when she called for a sick visit, the nurse prescribed Tylenol over the phone and she had to wait one month to see the doctor



## Health care needs of child

### Section 4 Questions:

#### Does your child without health insurance have a regular doctor?

- 10 of the 12 participants stated that the child did not have a regular doctor
- 2 participants stated that their child had the same doctor. These 2 participants utilized Harvard Pilgrim and Allen Berry Health Center

One parent spoke about the difficulties of having one insured child and three uninsured children. She stated, "My ten-year-old daughter, the one who has health insurance, who has the problem and is in a wheel chair. They have attended to her and have given her all that is necessary. She uses many things and they have even brought things to our house and I have not even had to go and pick them up. And I have noticed the big difference that if she didn't have health insurance then they wouldn't take care of her... but with the ones who don't have health insurance, they don't even want to take care of them. My daughter has everything, the same doctor since she was born and she is now ten years old. The same doctor keeps seeing her. But the others have seen different doctors and sometimes I have had to return home because there wasn't an interpreter and they made me wait a long time, or because they asked me a lot of questions about why I didn't have health insurance. I've had to return home without having them seen."

#### Where do you usually take him/her for care?

- The participants stated that they utilized the following places:
  - St. Joseph Clinic: 1 participant
  - Allen Berry Health Center: 1 participant
  - Family Health Services: 1 participant
  - Pawtucket Health Center: 1 participant
  - Central Health Center: 1 participant
  - Cranston Health Center: 1 participant
  - Harvard Pilgrim: 3 participants
  - Hasbro Children's Hospital Emergency Room: 2 participants
  - Combined sites: Hasbro Children's Hospital, RI Hospital, St. Joseph Hospital & The Family Van (on Wednesdays at the Joslin community center): 1 participant

#### Does he/she have any special health care needs?

- 7 participants told about their child's special health care needs
- 2 of these 7 participants expressed that they were concerned about the cost of the treatment or procedure that had been recommended
- 1 of these 7 participants stated that she did not know where to go for help, specifically which clinic for her daughter's operation

#### Special Health Care Needs:

- Child with vision problem and will need an eye operation in the future
- Child with ear problem who needs an operation involving tubes for ear liquid removal



- Child with frequent throat infections and mother was told to find a health insurance because the recommended treatment was to have the tonsils removed
- Child with asthma and mother has had to purchase medicine to control her child's condition. This mother had a friend who had an insured child whose insurance provided the child with a new asthma treatment machine. This friend gave this mother her old machine which she now utilizes to treat her daughter's asthma.
- Child diagnosed with asthma and uses inhaler
- Both children, one insured and the other uninsured, suffer from eczema. Mother uses the insured child's medicine for the uninsured baby. She spoke about spending \$40 for an antibiotic one week and then spending \$30 the following week for another antibiotic.
- Child suffers from eczema and seborrhis on the head

### Did you ever use the ER? What happened?

- 7 participants told their personal experiences. Each mentioned long waiting times.
- The participants took their children to the emergency room for the following conditions:
  - Eczema: 1 participant
  - High fever: 3 participants with 2 of these including vomiting
  - Asthma: 2 participants
  - Fractured arm: 1 participant
  - Throat infections: 1 participant
- 2 participants spoke of finding other ways to get the care their child needed by either treating the child with herbal remedies or taking the child to one's native country for care.

"One goes to the emergency room there to look for support and they don't do anything. That is what I see. Whatever I can do at home, I do before I take them. I don't just take them. My daughter suffered with asthma. I struggled and struggled and I cured her with herbal remedies and today, she doesn't have asthma," stated a participant.

A participant spoke about her experience of having a child with frequent throat infections who would finish a bottle of amoxycillin in 3 days and then be prescribed another bottle because the mother did not have the money to cover the cost of the operation to remove her tonsils. The mother spoke with the nurse and finally decided to take her daughter to her country to get operated on.

### Outreach Strategies

#### Section 4 Questions:

What are some ways we can reach families, like yours, who may not have enough health insurance? (Make a list of strategies and prioritize "Note: market health benefits or insurance as prevention)



**Top 4 Ideas:**

- Information offices in community organizations with outreach workers
- Direct mail
- Community Centers
- School flyers sent home with children

**Suggestions for Providing Information**

- Direct mailing informing individual once determined the child is uninsured
- Information provided at birth
- Direct mailing of information about insurance
- Information on your rights

**Outreach:**

- Meetings in the churches
- Work with the schools

**Media Campaign:**

- Commercials
- Latino radio
- Latino newspaper

**Target Population:**

- Target and provide support for low income families and single mothers with information campaigns
- Offer health insurance for parents

One participant suggested passing a mandatory law for the children regardless of immigration status. "Why can't they pass a law in the United States that by law all the children should have health insurance... the most important thing is the children?"

**Other family priorities****Section 5 Questions:**

Do you feel that there are other reasons, besides not having health insurance, that may prevent parents from getting health care for their children? Are there other issues that your family is dealing with that are more pressing or urgent than being without health insurance? Tell me about some of these. (Then prioritize these issues with the group)

**Other family priorities:**

- rent
- child care
- electricity
- gas

- car
- immigration status
- immigration papers. There are costs involved, for example to become a US citizen

#### **Prioritizing of other family priorities:**

- The participants reached consensus that the income they earn or receive is only sufficient for surviving and it is difficult to pay for health insurance which is very expensive
- The other priority identified was the family's legal status or immigration status. This pertained to issues related to being considered a public charge by the INS and to taking every measure to not jeopardize the entire family's situation. Some of the concerns expressed were:
  - 2 participants mentioned that families are afraid to apply for programs because of the fear and implications it will have with the INS..
  - 1 participant mentioned a lady who was very sick and was so afraid to go to the doctor for fear that it would hurt her with the INS.
  - 1 participant mentioned that families are afraid of being determined as a public charge by the INS and that it will affect them when they are changing their status.

One participant stated, "They have always asked me if my children were born here in this country. I have said no and then one is terrified because since they are not born here and that is the first thing they ask you and if they have papers from here."

#### **Special circumstances:**

- 2 participants were having difficulties due to child support enforcement policies. In each case the father was required to provide health insurance for the child by the court
- 1 of these participants, explained her experience of having her DHS case closed for not having her daughter on her father's insurance. The father lives in New York and when he becomes unemployed, her daughter loses her coverage. Her daughter has already had an operation and requires another. The participant explained that she would like her daughter to receive Rite Care and have consistent coverage.

### **Rite Care Recognition**

#### **Section 6 Questions:**

#### **Have you ever heard of Rite Care or Medicaid? What have you heard of it?**

- 2 participants had heard about the program and knew what the program was

#### **Have you ever heard of or seen their mail-in application?**

- 1 participant had heard of the new mail in application



**Has anyone here ever applied? What happened when you applied? What were some of the reasons that stopped you from applying?**

**Child support issues:**

- 1 participant who received public assistance had inquired with her social worker but was told her daughter could not apply because it was the father's responsibility to provide health insurance. This participant has had fair hearings to appeal this decision and was told she could not apply
- A second participant stated that her two older children do not have their father's last name and have health insurance through RIte Care but that her youngest child does have his father's last name and that when she applied she was taken to court. The father does provide child support but not health insurance because he does not have health insurance. She was told by the judge that the father has to provide health insurance.

**Immigration issues:**

- 1 participant mentioned that she did not think she could apply due to her immigration status and had consulted with an attorney who did not recommend that she apply

A second participant stated, "I asked if I could apply for a health insurance for my two children who were not born here and they told me that because they were not born here, they couldn't give them health insurance"

**Income issues:**

- 1 participant stated "when the two people in the household work, they don't give you help"

**Time availability:**

- 1 participant stated that she works and can not take time out of work to apply

**Recommendations:**

**System issues:**

- Address issues of proper notification for RIte Care cases dealing with reasons for dropping coverage, denials and eligibility
- If family is denied or coverage is dropped, send information on health centers, charity care in hospitals and emergency medical assistance. Any information for the uninsured
- Work with health care providers to ensure that they provide information on RIte Care and if possible enroll families
- Address issues on proof of income for individuals who can not prove their income.
- Resolve child support issues for cases when father can not provide health insurance or can not provide it consistently

**Public campaign:**

- Target immigrant families and address immigration issues such as public charge
- Focus on eligibility of immigrant children and parents
- Promote new eligibility of parents, in particular working parents
- Promote availability of assistance with convenient hours